



CHRC News

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INTRODUCTION

How do you assist a patron who is unable to read beyond an eighth grade level? Low-literacy consumer health material is often much more difficult to locate than non-English language information, yet the need for it is enormous. Cecilia Conrath Doak, in **Teaching patients with low literacy skills** (Lippincott, 1996) stated, "Literacy authorities tell us that 27 million American adults - nearly one out of five - may not be able to read a pamphlet."

In this issue, selected web sites which offer low-literacy or easy to read consumer health information are presented. However, keep in mind that what is easy for some consumers may be very difficult for others. As Boston-based World Education's glossary, at http://www.worlded.org/us/health/docs/comp/Introduction/define_terms.html states, "easy-to-understand" or "plain language" will depend on the needs, background knowledge, and interests of the readers. Keep in mind, too, that the only information available for topics such as rare genetic diseases or some forms of cancer is in medical textbooks or scientific web sites.

Also in this issue, some of the new titles in our consumer health collection will be highlighted in the **In Print** column.

As always, we would like to know what topics you'd like to see covered. Our contact information is on the last page.

In the News

The Public Library and Consumer Health

Martha Stone, Treadwell Library's Coordinator for Reference Services, attended the first **Public Library and Consumer Health** conference held in January, 2001. Subtitled "Meeting Community Needs through Resource Identification and Collaboration," it was sponsored by the Public Library Association (PLA), the Medical Library Association (MLA) and the National Library of Medicine (NLM), and was aimed at public library directors and administrators, collection development staff, community information specialists, and reference librarians. Some of the goals of this conference were to assist attendees in:

- acquiring resources and development tools to establish a consumer health collection,
- implementing processes for assisting patrons in finding health information, and
- developing the ability to determine the authority, accuracy, purpose, and audience of a health information web site and its appropriate use as a consumer/public resource.

**Public Library and Consumer Health
Conference Keynote Speaker, Tom
Ferguson, M. D.**

Tom Ferguson, M.D., is the author of a free web-based newsletter, available at <http://www.fergusonreport.com>. In his keynote speech, "The Empowered Medical Consumer," he discussed such topics as "patient-helpers" whom he described as a "vital new health care resource" and physicians' new allies in pointing out web sites. He also focused on "online disease clubs" for a wide variety of concerns that do not replace, but enhance, professional care. He cited the web based Association of Cancer Online Resources, **ACOR**, <http://www.acor.org>, a cancer information system currently offering access to 99 electronic mailing lists and a variety of web sites, as an example. As a "wave of the future" he predicted 24-hour a day live chat with "e-docs." An example can be found at <http://www.americasdoctor.com> (sponsored by AmericasDoctor, a pharmaceutical service). Tom Ferguson said he is delighted to hear from librarians at his email address, doctom@doctom.com

Cultural Competency Resource Center

Making sure that MassHealth insurance recipients are receiving health care services appropriate for their language or culture is the goal of the Commonwealth of Massachusetts' Division of Medical Assistance (DMA)'s new **Cultural Competency Initiative**, whose motto is "Cultural Competency, Quality Healthcare for our Members." The DMA has organized a Cultural Competency Resource Center

(**CCRC**) consisting of two librarian consultants, a library technical assistant, and a manager. At the moment, they do not have a web site. The **CCRC** Health Librarian Consultant is Peter Droese, at 617-210-5354 or e-mail at pdroese@nt.dma.state.ma.us

MEDEM

<http://www.medem.com/>

Seven medical societies, including the American Medical Association (AMA), founded **Medem**. Subtitled "Healthcare Information brought to you by the nation's medical societies," it includes information that had previously been found in the web sites of the AMA, the American Academy of Ophthalmology, the American Academy of Pediatrics, the American College of Allergy, Asthma & Immunology, the American College of Obstetricians and Gynecologists, the American Society of Plastic Surgeons, and the American Psychiatric Association. The **Physician Finder** section includes listings of specialists in several fields. Choose **Medical Library** to find consumer level information divided into topics, including **Diseases and Conditions** and **Therapies and Health Strategies**. Every document's "complexity indicator" is indicated, ranging from introductory through professional. For example, choose the broad subject area **Health and Society**, and click on **Genetics**. Choose **Human Genome Project** from the topics listed. There are six documents listed, all considered "general" reading level. The first is the Department of Energy's "Cloning Fact Sheet." You can also search for a word or phrase using the **Search** function. Documents retrieved are annotated with a "relevancy indicator." For example,

type **skin cancer**. The first document, from the National Institute of Health (NIH), is noted as being 100% relevant and written on an introductory level.

Low-literacy Web Sites

ARCH's Health Literacy

<http://www.mgh.harvard.edu/library/arch/literacy.asp>

Access to Resources for Community Health (**ARCH**) is a partnership among Treadwell Library, the MGH Community Health Associates, the Massachusetts Prevention Centers Boston Office, and the Chelsea, MA Health Department. The **Health Literacy** page includes links to pamphlets and programs on both local and national scales.

Medlineplus

<http://www.medlineplus.gov>

There are, to date, 64 documents available in the **Medlineplus** databases, in miscellaneous order. Just type the phrase **easy to read** into the search box. If there's a specific topic you're seeking, such as cancer, type the phrase **easy to read and cancer**. When available, **easy to read Spanish** documents are also included. Click on the topic, such as **Juvenile Diabetes**. [Do Your Level Best: Start Controlling Your Blood Sugar Today](#) (National Institute of Diabetes and Digestive and Kidney Diseases) is the only document with the **easy to read** designation. It covers a range of information but it should be noted that it does not include other information from the **Juvenile Diabetes** page, such as clinical trials, alternative therapy, or research.

Medlineplus Tutorials

<http://www.nlm.nih.gov/medlineplus/tutorials.html>

These 29 tutorials take users through information on a disease (e.g. inguinal hernia, diabetes), diagnostic test (e.g. colonoscopy, MRI), or surgical procedure (e.g. hip replacement, breast cancer surgery). Information is presented in short sentences, with simple illustrations, and medical terminology is defined when appropriate. In addition, each tutorial is fully narrated and a PDF version of the material can be printed. You can view the entire list of tutorials at the URL above, or you can link from individual health topic pages. Two tutorials, diabetes and hypertension, are available in Spanish.

Healthfinder

<http://www.healthfinder.gov>

Lagging somewhat behind **Medlineplus**, **healthfinder** includes 23 **easy to read** documents. Again, type the phrase **easy to read** into the search box. [Use Medicine Safely](#) is one of the documents, a succinct booklet telling how and why to take prescribed medications. **Easy to read Spanish** documents are included when available. **Healthfinder's** new web site is in beta testing, and comments are being solicited. It is being redesigned to offer more customization and personalization, at <http://www.healthfinder.gov/betatest>. Note that not all features are activated in this test site.

National Library of Medicine

<http://www.nlm.nih.gov/train/chi/easy.html>

"Easy to Read Consumer Health Information" is an annotated list of web sites

from federal, regional, and national organizations. **Easy to read Spanish** documents are included when available.

Health Promotion Council of Southeastern Pennsylvania

<http://www.hpcpa.org/materials.html>

Health Promotion Council of Southeastern Pennsylvania (**HPC**) is a non-profit corporation organized in 1981. **HPC**'s mission is to promote health and prevent disease, especially among those at greatest risk, through education, outreach and advocacy. **HPC** provides **low-literacy** health education materials in English, Spanish and a selection of Asian languages. The primary focus of most of these materials is chronic disease risk reduction and control, and features topics such as healthy eating, exercise, tobacco use, high blood pressure, and diabetes.

Oncolink

<http://oncolink.upenn.edu>

Oncolink is the University of Pennsylvania's excellent cancer information web site. Click on **Search Oncolink**, choose the **Advanced Query** mode, and from the drop-down menu, choose to search **Everything Except Citations**. Type the phrase **easy to read** into the search engine, and you'll find over 50 documents. "Recommended Reference List and Book Reviews" is one such example. Click on it to find an **OncoLink** book review of **Non-Hodgkin's Lymphomas: Making Sense of Diagnosis, Treatment & Options**. The **Oncolink** reviewing physician is quoted as

saying that it is an "easy to read book containing a lot of helpful information."

World Education's Health and Literacy Compendium

<http://www.worlded.org/us/health/docs/comp/>

World Education is a Boston-based non-profit organization dedicated to improving the lives of the poor through economic and social development programs. The **Health and Literacy Compendium** was written with two main goals in mind: to help literacy teachers and students find and use health information and to share literacy information and easy to read health materials with health professionals, community educators, and patients. Each citation includes a description and ordering information. At the back of the **Compendium** is a list of key organizational resources; publishers and distributors in the health and literacy fields, many of whom produce easy to read and multilingual brochures and pamphlets; and indexes by subject, language, reading level, and document format.

Readability Analysis of Consumer Health Materials

<http://www.nlm.nlm.nih.gov/scr/conhlth/read.htm>

Readability Analysis of Consumer Health Materials was compiled by Dixie Jones Reference Librarian, Louisiana State University Health Science Center Library, Shreveport, LA. The "Web Resources" section lists sources for finding information for patients with low literacy levels.

Clear and Simple

http://rex.nci.nih.gov/NCI_Pub_Interface/Clear_and_Simple/HOME.HTM

Subtitled "Developing Effective Print Materials for Low-Literate Users" this guide outlines a process for developing publications for people with limited literacy skills. The process was derived from communications, health education, and literacy research and practice. The five standard steps in developing print materials, each of which is thoroughly discussed in this web site, are defining the target audience, conducting target audience research, developing a concept for the product, developing content and visuals, and pre-testing and revising draft materials.

Keep in mind that some web sites place hyphens in the phrase **easy to read**. Thus, when you're using your browser's "find" feature to look for that phrase, you may sometimes have to insert hyphens.

In Print in Treadwell's Consumer Health Collection

A plethora of new titles are available in our Consumer Health section, and a few new books are highlighted below.

American Cancer Society's guide to complementary and alternative cancer methods / [foreword by **David S. Rosenthal**] / Atlanta, Ga. : American Cancer Society, 2000. Arranged in broad topic areas (mind/body/spirit; manual healing/physical touch; pharmacological/ biological), this readable guide covers many commonly used alternative methods, e.g. cat's claw.

Warnings are prominently placed, and bibliographic references include web sites.

Consumer guide to long-term care / **Gary Iminen** / Madison, Wis. : University of Wisconsin Press, 1999. The author is a registered nurse and health care administrator who has great familiarity with long-term care. This book is a readable guide that helps to demystify virtually every aspect of the field, both legal and medical.

The Consumer health information source book / edited by **Alan M. Rees** / Phoenix, AZ : Oryx Press, 2000. The sixth edition of this valuable text contains evaluations of over 600 books (of which 144 relate to alternative medicine), 170 popular health magazines, 1,500 English-language pamphlet titles, 640 Spanish-language pamphlet titles, and more. The content is all new and does not duplicate previous editions. This book is a treasure trove of information.

Dr. Susan Love's breast book / **Susan M. Love, with Karen Lindsey ; illustrations by Marcia Williams** / Cambridge, Mass. : Perseus Publishing, 2000. Now in its third edition, this fully revised guide is a tremendously useful "one-stop" for questions relating to breast cancer.

Grounded in Western science and research, it is also highly readable. There are extensive resources listed in the appendix.

Mayo Clinic heart book : the ultimate guide to heart health / **Bernard J. Gersh**, editor in chief / New York : W. Morrow, 2000. Attractively illustrated, filled with "healthy heart tips" and information on a wide variety of heart diseases, including chapters covering common tests, emergency

situations, and cardiac surgery, this book, now in its second edition, is completely revised and expanded.

Second opinion : the Columbia Presbyterian guide to surgery / Eric A. Rose / New York : St. Martin's Press, 2000. How to go about getting a second opinion; what questions to ask; how to get ready for surgery; and a brief guide to some common surgical procedures, are all presented in a matter-of-fact style.

We're here to help you! Please don't hesitate to contact us for assistance.

E-mail:

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<http://www.mgh.harvard.edu/library/chrcindex.html>

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